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PART 1 – INTRODUCTION: TURNING THE PAGE ON MEDICAL PATERNALISM – SLIDE #1 & 2

Good evening everyone,

If I stand here before you today, it is firstly because I am an experienced patient. For over 40 years, I've lived with several chronic diseases. Putting together all of my different hospitalizations, I spent nearly four years of my life in a hospital. Today, in addition to my family doctor, five medical specialties control my health on a regular basis.

With this in mind, I have indeed spent a lot of time thinking about our health care system and the evolution of a profession that I have always admired and respected: medicine

For now, my experience as a patient has convinced me of one thing : relationship that unites patients and their healthcare professionals must change. I believe that within the next 5 to 10 years, we must definitely turn the page on medical paternalism and adopt an approach where the patient and his family are treated as full partners of an interdisciplinary team.

Our health care institutions too often forget a simple thing: every patient and their family, at one time or another in their lives, will become a caregiver. Every patient will give to himself a certain form of care. **Patients ARE caregivers. All of them.** This statement should not be viewed as either spectacular nor militant. It is the simple reality. At one moment or another in the care process, patient will become caregiver.

Will they become proficient caregivers? This is a different story. It is a reality that millions of people experience today and it will be one of the main issues I will discuss with you today. I believe that it is your responsibility, as clinicians and educators to do everything possible to help your patients become COMPETENT caregivers, proficient caregivers.

You may say: we have always done it that way. But the truth is that you have most often started with an only vision of the physician rather than the patient. "How do we want tomorrow's doctors

to be like? What kind of competencies should they develop to respond to population's needs? These are the kind questions I hear in the medical education community. And they are good questions.

But we seldom hear doctors wondering what kind of patient do we want. We currently don't have a clear vision of the patient. He is often seen as being "taken care of", as being a passive receiver of care. So, all he needs be a good patient is to follow what one say is the right treatment, what one say is good for him.

So now, in a time where a competency-based learning approach is put forward, why not take this opportunity to rethink the entire curriculum of medical education from both a physician and a patient perspective, from a humanistic doctor and from a patient partner. Let's try...

PART 2 - SOCIAL CONTEXT DRIVERS – SLIDE #3

Care giving requires confidence. But sadly, confidence in our self-care abilities is the first thing we lose when we are sick.

For instance, let's just imagine... One of our four kids wakes up one morning with a sore throat. The first thing we'll do, is to observe what's happening and begin the health care process: "he must have caught something, so, he needs some rest, drink lots of water, take it easy for a few days, it will probably be ok".

But sometimes, it doesn't heal. So we start to worry a lot more. We *check* our kid again and again. We take his temperature, look for swollen lymph nodes, even look in our kid's mouth to see how does the throat looks like. Sure, we're not doctors, but we know a great deal about this stuff: we have four children, there is always one of them who has a running nose. We have a feeling, an intuition about when to worry. This is what we're going to call an "experiential-based knowledge". But sometimes this knowledge is not enough. The child is not doing better.

So we go see the pharmacist and seek for an advice. Maybe even do some research on the Internet? Ask our friends, our family. But sometimes, at the end, we're going to end up in the physician's office. Now, I want you to realize that until that moment, we have been the coordinator of the all caregiving process. We have been not only a part of the team, but the leader of that team. But our medical expertise is limited and we now need to seek for some expert advice.

Unfortunately, at this precise moment when we enter the physician's office, we are usually no longer considered as a caregiver. We are considered as a care-receiver. During the ten minutes we'll spend with our doctor, he is going to diagnose and treat. He will prescribe antibiotics and tell us how to take them.

At this precise time, our knowledge is not always welcomed, not always recognized, and it is certainly not valued and developed enough. At the end, we'll have a specific treatment solution but our level of confidence as a proficient caregiver will mainly depend of how we've been able to express ourselves, how we've been listened, reassured, accompanied...

... How our experiential-based knowledge has been valued and our competencies enhanced for the next same care problem... How our physician helped us to become a better caregiver... How he respected our rhythm, our capacities and our singularity as a human... How he reinforced our leadership on our own health process. That's the main trigger of what's going to happen next...

That's the heart of my message as a person living with three chronic diseases. First I suffer from hemophilia. As a severe hemophiliac, I use blood products very often. Back in the early 80s, several viruses including AIDS and hepatitis C contaminated them. I contracted both around the age of 12. Needless to say that the relationship between patients and their health practitioners and the development of *patient's* skills have been central to my life and to the lives of many of my peers.

But before talking about my experience, I would like to share with you a few key statistics that you already know. But let's just remind...

- SLIDE #3

First: **50% of the population in North America, — and this is also true for Western countries in general — suffer from *at least one chronic illness*.** This means we do not live in a reality of acute care anymore, with its only focus on diagnosis and curing. We are now facing a new dominant paradigm where a majority of patients will live long lives with their disease. This is worrying, of course, but it also calls for a unique opportunity to rethink our medical education strategies.

- SLIDE #4

Here's another figure: **50% of these patients with chronic diseases don't properly follow their prescription.** This means that half the patients you currently treat struggle in the way they handle their treatment, the treatment you prescribed.

What I can tell you is that the vast majority of people who suffer from a chronic illness all share one simple goal: to change their mind set regarding their illness, to regain hope and trust in themselves, to regain autonomy in spite of the disease. And the only way they can achieve this is by becoming autonomous *proficient caregivers*. Do they know how to do it? It's another question...

- SLIDE #5

Some may believe the Internet is the solution to patient education... I believe they are wrong for now. Health information currently available online is poorly organised and very chaotic. Most information found online is either difficult to validate, is often disclosed by pharmaceutical companies, or it is the kind of information given to our medical students. It is hardly usable by the average men and women you see in your practice.

The most effective way to put an end to this situation is to ensure that our health care institutions become learning environments for patients as well. It is more than time that we educate the, millions of people suffering from a chronic disease getting through their illness. It works. I know it. I'm here to testify about that. It worked not only for me but for my peers also. We experienced it so many times...

PART 3 – HEMOPHILIA: A VISIONARY COLLABORATION MODEL – SLIDE #6

This is me – aged 3 — with my mother. You will notice I had more stomach back then. At this point in my life, I only suffered from hemophilia. I had the chance back then to experience an extremely innovative care management. In the 70s, hemophilia clinics were true healthcare laboratories, that were everything but mainstream.

These clinics developed an “avant garde” healthcare philosophy where the education and the training of their patients and families were fully integrated in the care process. You can imagine, I would bleed 200 times a year. Each time my parents would fail to get my bleeding under control, we would end up back in the hospital.

Our health teams proposed logically: "Let's work in partnership with you. Lets' try to transfer some of our expertise to you, so you can be more independent". And it worked for a large majority of hemophiliac families — regardless of their social status or their cultural background.

The hemophilia community eventually proved it was possible to live a normal life with continuous training. I was able to progressively upgrade my health judgment and know myself better through the illness. Doctors are specialists of the disease. Patients are specialists of THEIR illness and this is an important distinction.

- SLIDE #7

To give you another concrete example: as you can imagine skiing is extremely risky for a hemophiliac. But because I had a capacity for health judgment, it was easier for my doctors to trust me. They knew that I'll take a little more risks, but on the other hand, I will be able to know my own limits. And if something happens, I knew how to treat myself". In fact, I started transfusing myself intravenously from the age of six. And I've been safely managing my skiing passion for more than 35 years.

PART 4 - EXPERIENCING AIDS: PATIENT'S EXPERIENTIAL-BASED KNOWLEDGE AND CHOICE – SLIDE #8

For us, hemophiliacs, the real challenge began in the 80's, when 90% of us, in Canada and in most European countries, were contaminated with the AIDS virus. We then entered a totally different world, living with a fatal and incurable disease that was also an huge source of stigma.

- SLIDE #9

This is me, aged 15, newly contaminated with AIDS.

From the early 80's to the mid 90's, there was no effective solution to fight this disease. Scientific knowledge was very limited. We didn't even know what this virus was and how it worked.

But an amazing phenomenon took place: We, as infected people, just drew from our daily lives' experiences and transferred this knowledge to one another. We set up communities, exchanged our tricks and built experience-based knowledge. Regardless of our backgrounds, social status or education, we just watched what was happening, tried on different things and helped each other.

As haemophiliacs, we had demonstrated patients could develop their skills and become, with the help of scientific information their own proficient caregivers. With AIDS, we demonstrated patients could become proficient caregivers based on their every-day experience of the illness and on a community-based peer-to-peer education.

This was a turn over in regards to patient education and more mainstream practices like self-management or share decision-making.

On the other hand, while patients became proficient caregivers, they also developed the ability to make free and informed choices; choices that could often differ from their health practitioners' perspective, choices that you, as professionals, will sometimes find hard to accept.

For instance, in '95 the famous AIDS protease inhibitors, the tri-therapies, appeared. Finally, we had a treatment for the AIDS virus. The problem is that these drugs had many side effects. At that time, most of us, survivors, were proficient patients, who had been living for 15 years without any form of efficient treatment. We had maintained a fragile balance between the disease, our professional careers and our personal lives.

Then all of a sudden, we were told to take this new treatment that would make our life “Hell” but that would ensure we would not die of AIDS. A lot of us refused at first and decided to wait in order to better evaluate the benefits and the disadvantages of this new treatment; like experienced people does.

Some of our health practitioners reacted very badly to this refusal and decided not to follow us anymore. There was a profound misunderstanding of our decision; a feeling we had just refused a long-awaited expertise. This is when we realized how big of challenge patient education was, how it was narrowly linked to health professional education...

Yet other AIDS clinics were far more visionary. They quickly realized that the experience-based knowledge of their patients was extremely relevant for their own skills and practices. They also believed a large part of clinical decisions belonged to patients because it was simply the best way to manage risks with them in a very uncertain clinical setting... And, eventually, it was the best way to avoid legal pursuits.

These teams were able to question their “expert” position in order to include their patients in the clinical dynamic. In this regard, patients had become partners in their medical choices and solutions.

PART 5 - EVOLUTION OF MEDICAL EDUCATION: A WAR AGAINST DEHUMANIZATION – SLIDE #10

To achieve such a sharing of responsibilities and risks, we need the paternalistic practices of health professionals to give way to a more collaborative approach; an approach that is better aligned to the current social issues. It is only then that patients’ empowerment through their illness will be seriously integrated into the clinical process as much as the healing of their pathology.

- SLIDE #11

Today, several institutions integrate patient’s skills development in their healthcare strategies. But let’s be honest: there is still much to be done before healthcare institutions become true learning organizations for both health professionals and the millions of patients with chronic diseases and their families.

But above all, we need to support our educational institutions, namely our medical schools, to teach differently and to rethink their curriculum in new ways.

The idea here is simple. Our young doctors must be experts in treating diseases, obviously. But they must also be able to work with patients on the achievement of their life projects rather than aiming to cure them entirely or strictly preventing complication... simply because it's simply impossible to do so for a majority of them with chronic disease!

It's may be time not to forget that medicine is above all an art that goes beside scientific expertise. We must make sure that the medical profession doesn't become dehumanized, demobilized, full of scepticism and cynicism. Through my day-to-day experience, I feel often this trend and it's a sad situation for the patients but also for doctors.

In the same line of thinking, the challenge of interdisciplinary is still a trigger. Indeed, too many patients continue to witness the difficulties face by their health professionals when it comes to communication, collaboration, align their practices and trust each other. When collaboration does not work, we — the patients — must often overcome these collaborative deficiencies ourselves. Please, never forget that. At the end we are always the last net.

PART 6 - EVOLUTION OF MEDICAL EDUCATION: STARTING FROM BOTH A VISION OF THE DOCTOR AND A VISION OF THE PATIENT – SLIDE #12

So today, we propose to involve patients at all stages of medical training. We must envision the patient differently and eventually re-think the type of medical interaction we have with him.

What is a good patient? What kind of patient do we want to deal with in the future? For too many health's professionals a good patient is yet someone who is not late for his appointments, who will take his medications exactly as prescribed, and who will not challenge expertise authority. Let's go further... please...

Let me propose a vision of tomorrow's patient, a vision of a patient partner in care, the vision that we developed at Montreal University: A patient partner in care is a patient who's is kept in movement, who's learning and evolving at his own pace, according to his abilities, his values and his life project. A patient in care feels part of the healthcare team and assume, at his rhythm and progressively is caregiver role. Maybe he will progress quickly, may be not so quickly, but he's in movement.

With this new perspective, our students need to develop more and more the ability to embrace human complexity, adapt themselves to the different individuals they will treat without feeling frustrated or that they have failed.

Collaboration is many things but it is primarily the ability to accept the other as he is, with his color, his physical appearance, his singularity, his suffering and to be able to read him and to

follow his own rhythm, to accompany him in his health successes but also, and maybe before all, in his failures.

We are talking here about a two-way relationship that must be experienced by both the physician and the patient. Each must value the quality of their interaction and participation. This is also why any deep reflection on evolution of the curriculum of medical education should start from both a vision of tomorrow's doctor and a vision of tomorrow's patient... And, like this, ultimately, come to a share vision of a *partners-in-care* relationship.

PART 7 - EVOLUTION OF MEDICAL EDUCATION: THE ESSENTIAL TEACHING OF HUMANITIES – SLIDE #13

All of this cannot be done without a rehabilitation of the humanities in our medical programs. In recent years, the introduction of competency-based learning approaches allowed us to realize that it was essential that collaboration, communication, professionalism, and health education be taught in a longitudinal manner.

Today, it is time to realize that to achieve such a change, we will need to go further than teaching our students the universal principles of communication in a checklist of 70 systematic steps. We will have to provide our students with reading grids based on the fundamental aspects of sociology, psychology, economics, anthropology, and ethics.

Not to do this is to consider our social realities as monolithic. It is prevailing an approach where the universalism of the disease outweighs the singularity of the human. It is to stick to the old, paternalistic biomedical paradigm.

It is to purposely maintain this healthcare war metaphor where the main objective is to kill a pathogen enemy, to restore what was lost instead of accompanying a person in his suffering, his healing, his dream, his life...

I have almost no chance today of experiencing a full recovery before the end of my life. It's difficult for me but it is also difficult for my doctors. But, I do not ask them to cure me. I only ask them to understand where I am in my life, to help me take better decisions and realize my life projects — in spite of my disease. This is how I shape with them a care plan customized, tailored, to who I'm and not just my anticipated needs.

But to succeed, we must stop thinking that we can make these care plans without the patient, by simply applying a universal, repeatable approach that works for all humans and contexts. We must stop being afraid to enter the heart of the people we treat because we do not want to waste time or because we don't know what we will find there.

Sustainable change of our medical curriculum requires that the humanities, along with the medical expertise, be taught in an integrated and longitudinal manner. Our students need to have some more protected and controlled thinking space, to analyse, to reflect on their patient-doctor relationship, to share these experiences with their colleagues as well as with real patients.

It is much wiser and realistic to prepare our medical students to face uncertainty and ambiguity which are inseparable factors of human interactions. Let's innovate more and more on how to teach humanities to our medical students in order to re-introduce the essential foundations of the patient and health practitioner's relationship in the heart of medical curriculum.

PART 8 - EVOLUTION OF MEDICAL EDUCATION: PATIENTS AS TRAINERS WITHIN MEDICAL FACULTY – SLIDE #14

In this regard, I believe patients must play a major role in medical training and research. Our medical students must be able to experience the physician-patient relationship in a protected environment. This is an extraordinary opportunity to understand how to build a strong relationship with real patients outside of difficult clinical settings.

The presence of patients in academic settings provides students two different sources of knowledge that are at the core of their practice success: those of their peers and those of the patients. Students will even get more familiar with the world of patients, how they perceive and live with their illness.

I am not saying that both expertise are equivalent. Patients can never replace a doctor's ten years of study. But doctors can also never replace the knowledge built by a patient during his journey with an illness. Here, we are talking about a complementary understanding as the foundation of a constructive learning experience.

At the University of Montreal, patients' participation to several working tables has indeed enriched the ideas and recommendations of our MD curriculum review. Many of these recommendations now constitute the very heart of the innovations of our future MD program.

These patients are also key partners in new educational activities as *patient-as-trainers*. We strongly believe it is essential that the participation of patients goes beyond the simple simulation or role play. In a curriculum where competencies development and social sciences will take an important place, we believe patients who are properly selected and trained can contribute further.

These *patients as trainers* can participate to education of social sciences and the development of our students' communication and collaboration skills, above theory and concept. Paired with teachers as co-trainers, their participation should not be limited to the simple expression of their

life's testimony or as study object. Our goal is to have them become true guides in the exploring and understanding of the world of patients.

We can now count on twenty patient trainers, paid and considered as members of the education medical community. They were carefully selected, coached and involved in many of our educational and research projects. They come from very different social and educational backgrounds and are affected by different types of diseases. Some of them are also family caregivers.

We do not compromise on the quality of their involvement in each experiment and try to make their role richer and closer to that of a real teacher. It is essential that the educational duo they will form with their health professional counterpart becomes a true example of a constructive relationship for our students.

- SLIDE #15

Those experiments have given us very encouraging results. Our selected patients have trained more than 3000 health sciences students so far on the concepts of a Partnership of care and collaborative practices. And to get there, everything was carefully planned: educational objectives were modified accordingly, along with tutors guides, online modules and the complete re-engineering of these training activities.

Today, at the Faculty of Medicine of University of Montreal, the Office of the patient partner expertise - which I am currently directing - has the mission to represent patients and manage patients-as-trainers within the Faculty. We are currently creating strong ties with the different instances within the University and are progressively earning our legitimacy on all Faculty levels. It is an extremely rich and promising process.

This patients as trainers initiative lead by patient may be the reason why our medical students will not forget, once in their work field, that despite the difficulties and crisis they face, a partnership is still possible. **That this partnership in care is their main defense against discouragement and their way to find meaning in challenging times.** We believe strongly it is the future of any healthcare profession in the light of the current social issues.

PART 9 – CONCLUSION : PROMOTE A HEALTH VISION WHERE THE ABILITY OF INDIVIDUALS TO TAKE CARE OF THEMSELVES IS A PRIORITY – SLIDE #16

Finally, the arguments presented in this conference are quite simple.

Ensure that your patients become proficient caregivers, based on their experiential knowledge, by integrating them systematically in their own care process and by educating them about their medical condition. This patient involvement is crucial in order to be able to cope with the growing

needs of chronic diseases and to try something different to increase patients' level of compliance. Let's them surprising you, it can be as simple as that.

Be sure to prepare our future doctors — and certainly some current physicians — to this new collaborative reality, this new partnership. That's how we'll avoid a strict one-way approach in favor of a learning approach based on collaboration and communication.

Invite patients in your Faculty, give them a prominent place, use them as a support in your great educational mission. And most importantly, give them a certain power of influence. They will come up with new ideas, enable you to position yourself differently and even help you settle some difficult debates.

A patient will share with your students the richness of his world, his experiential knowledge and will become a mentor when it come to living with an illness ... This will enable you to adopt a health vision where the ability of individuals to take care of themselves is a priority.

Today our health systems are facing a major growth challenge. Patients have a role to play in order to help you facing it. You're not going to succeed without them. You're not going to succeed without their implication at all level, care, education and research. It's a huge change of mind set because, to many times yet, our students are trained to be heroes but what we need it's partner, partner in care.

Take care of yourself!

I thank you for your time.

- SLIDE #17